

Candace O'Connor's story of



Multiple sclerosis is a neurological disease that attacks the nerves. Now considered one of the autoimmune diseases, there haven't been any major advances or cures in the six years since Mummy died in 1998 at age 78. Even before that it was considered a mystery. Doctors agree however that people with MS should try to reduce the stress in their lives as much as possible.

That '78' is momentous for someone with MS. No one expected her to live that long. The fifth child, June Beverly Van Alstyne was born prematurely in Rosetown, Saskatchewan in 1920. As they didn't have incubators they wrapped her in cotton wool and put a light over her to keep her warm. Her parents were farmers, with two sections (1240 acres), and she often rode a big work horse to the one-room school where she excelled. From all accounts she was precocious and favoured, the only one of the children who could outwit my lawyer-turned-farmer grandfather, who used to quote Shakespeare and the bible and drink rum by the barrel at Christmas time.

She was about 12 when the droughts of the depression forced them off the farm. The final straw: whenever Granddad tried to dig a new well he got oil. She began High School at Jervis Collegiate in Toronto and would stay up all night writing political diatribes to her Uncle Everton in B.C. She was a committed Socialist; he was not. Around this time Mummy began to faint a lot and so was called "Floppy Jo' by her brother Barry, a nickname that stuck throughout her life. Soon Mummy 'matriculated' (as they used to say) and went to work as a secretary.

"Five foot two, eyes of blue" she was working for the Department of Health for the Ontario Government where she met a handsome mail-boy, Bill O'Connor, fresh from Sault Ste. Marie, with a tenor voice and looks to die for. They used to tell of how he came for Sunday dinner and was introduced to the family's awesome homemade horseradish. He was told to put about a tablespoonful on a bit of meat, and inhale as it went into his mouth. For some reason he forgave them! He got a regular gig on CFRB radio, and became something of an up-and-coming singer. When the war broke out he enlisted as an officer in the Navy, and Mummy went to Halifax and married him in a royal blue velvet suit with matching buttons; such a beautiful bride for a dashing officer!

Transferred to Winnipeg, Dad helped train prairie boys who didn't know how to swim, and Mummy learned to cook. One night, she made spaghetti for an officer who came to the apartment for dinner and threw the sticky goo onto the ceiling where it obligingly stuck and hung; Mummy told the story later with great humour!

In 1941 Dad was sent to Londonderry, and somehow became involved with the Canadian Navy Show, because after the war ended, after Mummy's brother-in-law was killed and she had helped her pregnant sister Fran through that nightmare, Mummy flew to England and they set up house in Hampstead, while Dad performed in The Navy Show in the West End. Mummy loved her new life, but her health suffered until doctors in London removed a bit of her colon for what they diagnosed as diverticulitis. She jumped back into her role of successful actor's wife. But then she started to suffer fatigue and pains and weakness and odd things that the doctors were convinced were hypochondria. They were sure that once she had a child she'd be all right. And for some reason, being pregnant does seem to bring remission for women with MS...

I was born in May, 1947. They bought a lovely row house in Chelsea, my grandmother came for a visit that lasted a year, and Dad opened at His Majesty's Theatre in Brigadoon, singing "Come To Me, Bend To Me" and 'I'll Go Home with Bonnie Jean' which made me doubtful about his reliability. They were Canadian heroes in London after the war, Dad was a star, and life was good. They threw wonderful parties; my

mother would dress up and put on make-up and not wear her glasses and looked beautiful, a flirtatious as well as gracious and amusing hostess.

After "Brigadoon" Dad sold the house in Chelsea planning to return home, but then he got another show, and we rented an apartment in Hampstead. Mummy walked me to school, about 4 miles a day for her, but she began to walk askew, bumping into me all the time. She always blamed me for not walking straight. Dad started giving her B12 injections once a month for pernicious anemia to keep her energy up. We always enjoyed the following week because she would feel much better and be her own self. In between she would get snappy and tired — "run-down". "Love From Judy" ran for three years, and then there was another musical, "The Little Minister" (adapted from J.M.Barrie's play). Dad reintroduced "He's Got The Whole World In His Hands" to the world (and him playing a white minister!) and the opening night audience stopped the show and he had to sing it twice more — we all thought it would be a hit. But the show closed in less than a year, a terribly short run for a London musical, and Dad's star began to fade. Anyone in show business knows the stress associated with not working: no money, no prospects, auditions that are approached with hope and most often followed by despair, and then the euphoria of work! It's a roller-coaster ride, the worst of all possible worlds for someone with MS. Stress is to be avoided at all costs — what an impossible combination!

Mummy went back to work – at Shell International – the only employee given an "A" rating that year. But her health deteriorated so badly she was forced to take six weeks absence (on full pay), then six months, then a year. They finally replaced her – with two people. Shell wanted her back, but she couldn't get over her stomach ulcer and a fatigue so great she couldn't function at her normal energy level, which was full tilt. When Mummy started a job she went at it until it was finished – she never paced herself. It didn't matter if she was sewing a suit on her old Singer hand-machine, typing a long report (she did 120 words a minute on a Selectric typewriter!) or managing the Shell typing pool of twenty "girls" with whom she soon became close – some became friends for life! They'd type a letter and get it back to their "bosses" in 8 minutes, a standard Shell asked for when they hired Mummy, never expecting that she and her staff could and would actually deliver!

Daddy quit show business; he returned to Canada and a straight job in Montreal; Mummy started drinking gin at noon. I dropped out of school waiting for our flat to sell, helping Mummy off the bathroom floor, reading Jane Austen and the Russians. When we got back to Canada, I stayed with my aunt and uncle in Brooklin, Ontario, and Daddy and Mummy came to visit on weekends from Montreal where they both worked. Mummy hated that we couldn't afford to have the family together and lost huge amounts of weight, she looked awful, and her balance deteriorated. While Dad and my uncle played golf on Saturday and Sunday, sometimes 36 holes straight, she would drink with my aunt.

After two years Dad got a job with the Cancer Society in Ottawa, and I rejoined them there. Mummy found work with the Canadian Medical Protective Association which was probably the worst place for her, given her distrust of doctors. But it was her boss there who finally insisted that she be tested for MS, and of course, the results were positive.

The next thirty years saw a tremendous decline in Mummy's health and quality of life. Her drinking increased proportionately to her disease, as did Dad's hours of work and golf. I visited her several times a week until my daughter was born, and then we bought a duplex so we could all live together, and she saw my aunt and uncle on the weekends. Our focus became to try to salvage her shrinking world, bring some joy, some hope, some normalcy into a life dominated by her descent into incontinency, falling, broken bones, walkers wheelchairs, bedpans, moves and renovations to allow for the same... and the unmitigated

loneliness of life as a shut-in. I became an unwilling enabler in the liquor department, as well as her taxi service, laundry service, cook, cleaner and confidante. Dad rose two or three times a night to help her to the washroom. He was always sleep deprived, but he never complained. Nor did she. She just got feistier. Then finally, she just got tired.

My mother died at 78, with grace, fortitude and amazing courage. But she had been dying for so long, bit by bit, and we had had to hold on to our memories of what she had been for so long, my Dad and I, that we felt as if her death was the end of a bitterly long campaign. My mother died at 78. At long last. It was a blessing.